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ABSTRACT

This report describes the development of integrated community services for people with severe disabilities by Job Path, a New York City agency which currently provides services to approximately 250 people. A current emphasis of the agency is increased consideration of the individual's life outside of the work setting. Critical factors in the agency's success are explained, including: (1) establishing a clear direction; (2) defining staff responsibility; (3) developing shared leadership; (4) adopting flexible approaches; and (5) collaborating with policy makers, other service providers, and families. Three case studies illustrate the agency's attention to individual needs in the areas of independent living, personal interests, and recreational activities. (DB)

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JOB PATH: SHIFTING THE FOCUS BEYOND JUST WORK

by

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1996

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Introduction

The development of alternatives to traditional day services is one of the greatest challenges facing organizations that support people with severe developmental disabilities today. Efforts to support community integration have generally been limited to people who can hold typical jobs with minimal or short term assistance (Brown, Udvari-Solner, Frattura-Kampschroer, Davis, Ahlgren, Van Deventer, & Jorgensen, 1991; Taylor, 1988). Few agencies have successfully developed services for people with whom it is difficult to determine their interests and choices and who need intensive long term assistance.

Recently, Job Path began to focus on developing community integrated services for people with severe disabilities. Given its history and approach to service provision, the agency's movement in this direction appears to be a natural development. We learned about these efforts during a visit to the agency in February, 1995.

Leading the Revolution

Job Path originated as a demonstration project of the Vera Institute of Justice in New York City. Founded in 1961, the Vera Institute has continued to have a concern for fairness and injustices within service systems. Early successes with demonstration projects in the area of criminal justice led to work in the areas of child welfare, health and employment. In the late 1970s the Vera Institute assisted people involved in the criminal justice system to find and hold mainstream jobs.

Job Path was formed in 1978 with the goal of applying this approach with people who have developmental disabilities. This occurred when the largest institution in New York State

was mandated to close and there was a strong movement toward sheltered workshops and other alternatives that were smaller but still facility based and segregated. Administrators of the Vera Institute, however, were committed to developing integrated alternatives.

Job Path has never operated segregated facilities. It now provides services to approximately 250 people, at any given time, in community jobs and activities and employs up to 30 staff. The agency receives funding from a variety of sources including: the New York State Office of Mental Retardation and Developmental Disabilities, New York City tax levies, the New York State Office of Vocational Rehabilitation, the New York City Department of Employment, and employers themselves.

Job Path has developed the capacity to support people with severe disabilities over time. The agency's philosophy and practices it developed early on have contributed to this capacity. Most importantly, administrators learned that some people need long term assistance if they are going to succeed. Job Path developed a supported employment approach that does not involve a predetermined time limit to services. Emily Ellis, Deputy Project Director of Job Path, explained:

> ...one of the things we all bought into from the very beginning was we didn't want to do a place-and-run technique...employers and participants and their families know that if you're part of Job Path, our commitment is to work with you, as long as you're living and as long as we exist.

Although the agency provides as much assistance as an individual needs, members also learned early on the importance of facilitating natural support. According to Fredda Rosen, Job Path's Director, "We found we were providing more support for people than they really

needed." Emily added, "An employer told me this. It wasn't my brilliant thinking. I'm sitting there watching these guys work, and he told me to get lost, that it was interfering. It's keeping them from becoming a natural part of their work environment."

As the agency developed a stronger vision of integrated services, administrators at Job Path recognized that opportunities for people with severe disabilities were still limited. Fredda noted:

> Then we began seeing that as supported employment programs began developing, people with more severe disabilities were being left out of this revolution. The revolution was going on, but it wasn't reaching the people for whom it was intended, and so we became interested in trying to begin to work with people with more severe disabilities.

The agency has developed several projects to support people with severe disabilities. They have focused on developing services for people who have been considered unable to work, particularly those who attend day treatment centers. A very new project is designed to provide integrated opportunities for students as they graduate from school. In the effort to design more responsive services for people with severe disabilities, Job Path has expanded its focus beyond work. It has found that effective services require consideration of an individual's whole life.

During our visit to Job Path, we focused on the agency's efforts in this new direction. We had the opportunity to meet with individuals receiving services and their families as well as a number of staff and administrators involved in the projects. The remainder of this report describes how the agency developed this new approach and the outcomes it has been able to achieve.

Developing a New Approach

A number of factors appeared to be critical to Job Path's success. They include: establishing a clear direction; defining staff responsibility; developing shared leadership; and adopting flexible approaches. In addition, their success was based on collaboration with policy makers, other service providers, and families.

Establishing a Direction

Job Path's direction has evolved from a process of developing services for a small number of people and reflecting upon this experience. Through their initial effort to support people to leave day treatment centers, staff faced several challenges that have, through reflection, guided the agency in expanding its focus.

A primary concern was that it was difficult to determine the interests of people who were attending day treatment centers. Lisa Pitz, a staff member of Job Path, expressed this concern as follows:

> ...these are people who had transitioned right out of the school system into day treatment environments and had never been offered a whole lot of choices. They weren't even sure what they wanted to do. The concept of work was so abstract to them.... So it was really hard using existing supportive employment techniques to help these guys make the transition to supported employment.

Also, staff found that people lacked relationships outside of the day treatment centers, which presented another challenge. Lisa noted:

...it was such a part of their life for so many years that those were all their friends. Those were the only relationships they had, beyond their family. So plucking them out of there was really difficult for them and they felt a real sense of separation. We had one young lady who had three jobs and she sabotaged the first two jobs, and the reason why was she wanted to go back to day treatment to have her social hour and talk to her friends.

Recognizing that support of people with severe disabilities required a very different approach, the agency planned a retreat to discuss what staff had learned and what they needed to do differently. They came to two basic conclusions. First, they could only support people effectively by expanding their focus beyond work. People needed opportunities to develop their interests, build social relationships, and in some cases improve their living situations. Fredda explained, "We're going to help people do whatever it is they want to do. We're going to stop a complete focus on work." The second conclusion they reached was that in order to provide such extensive support, the program must limit the number of people they would work with.

As explained earlier, the effort to support people with severe disabilities was designed into several small projects. For example, in one project called the "living resources" project, a team of up to four staff develop opportunities and provide assistance for people to get involved in community activities. Currently, they support 13 people. In another project one staff person develops living situations for eight people. At the time of our visit the agency was in the planning stages of a collaborative project with local schools to support students transitioning from special education programs.

Shared Leadership

Members of Job Path maintain a clear commitment to support people with severe disabilities. The actual development of services, however, continues to be a process of learning as they go, due in part to the fact that there are few examples of integrated services from which to take direction.

In their everyday work, staff learn through discussion and problem solving rather than through authoritarian leadership. When individual staff described dilemmas they experienced, they emphasized alternative solutions, and not correct answers. They view problems and dilemmas as an expected part of their work and come together to address them. This has resulted in staff taking direct responsibility for their work, a most striking characteristic of the agency.

Defining Staff Responsibility

Staff of Job Path value the team approach in their work, but not in the traditional sense that members are responsible for a specific aspect of people's lives. As Fredda stated, "Everybody's going to do everything." Team members work together, thinking about all parts of a person's life. Fredda and Emily are active members of this team. They personally know all the people receiving services and work closely with staff.

In the effort to involve people in community activities, staff work in pairs. For example, Andrew Auten and Yvonne Oliver have primary responsibility for specific individuals, yet they are also responsible for knowing the individuals the other is supporting. They often fill in for each other and share ideas.

This strategy worked effectively in the case of a young man whom Yvonne assisted. For several reasons, there came a point when they realized it would be better if Andrew worked with him. They agreed to shift responsibilities in this case, which led to a better sense of the man's interests. Cooperation seems to be an important part of their work.

In addition to adopting a team approach, staff roles have changed significantly in terms of how they spend their time. Staff spend much of their time getting to know people and their families, hanging out in their homes and neighborhoods. According to Emily:

> We are really listening to folks and building, structuring our work with them. We're more like friends and buddies with people. I love doing this stuff because folks teach you, and we sit around tables on Sundays and Saturdays, and there's something very powerful in that kind of statement. It really changes the balance.... You're empowering people and they're empowering us at the same time because it opens up all kinds of ways to begin to look at and appreciate. I think we've grown so much ourselves because we don't put limits on what people can do because time and time again our relationships are showing us.

Fredda added, "Those relationships are very valuable. It requires a different kind of involvement and talk about going outside of your comfort level. You have to be able to go beyond your professional counselor role."

A large part of what makes the work challenging and unique is the fact that they live and work in New York City. Community involvement in New York City is complicated. In

such a large city, transportation and safety can become real obstacles for individuals. The size and complexity of New York also hinders opportunities to develop relationships.

For example, it can be a challenge for people to simply get from one place to another. Some people use taxis; others have learned to ride the subway. Whatever form of transportation people use, "street smarts" are necessary to live in the city. Fredda explained how they are working with one man who has a habit of approaching strangers on the street. She expressed concern, "I mean, he might get killed, seriously....This is New York City. You don't get in someone's face and he does."

Many families live in neighborhoods they consider to be dangerous. In the effort to avoid risk, they have a tendency to keep to themselves. This is an additional difficulty which impedes the development of natural supports in a neighborhood. Staff members must work with families to figure out safe ways for individuals to get involved in activities and meet people.

Adopting Flexible Approaches

Unlike traditional approaches where there are predetermined outcomes, Job Path views each person as having unique needs. The goal is not to fill up a person's daytime hours with pre-established activities; instead, staff investigate opportunities based on people's interests in their own neighborhoods. As Andrew explained, "We really don't have a set of established relationships and resources that we always go back to again and again. Each new person gets a brand new set of resources that we try to develop."

These opportunities take time to develop and the approach requires flexibility. Most people are not headed toward full time jobs and it is usually quite a while before their days are filled with meaningful activities. Fredda explained:

> When you're doing individualized work its not going to work out that you're going to get a 9:00-3:00 something five days a week, at least not right away. First you're going to get one piece, then somebody might be ready to take on something else, then a third thing, and one thing falls through. It's not neat.

With one man, for instance, it took nearly two years to develop opportunities. Now he spends his day working part-time at Wendy's and going to his neighborhood library; soon he plans to join a gym. During the process of developing these situations, he continued to attend a day treatment center on a part-time basis.

Situations like this have been a challenge to manage financially. While staff spend much of their time getting to know people and developing opportunities, administrators are concerned about how to get reimbursed for these services. The agency has a steady base of traditional funding through its supportive employment program and has been awarded federal grants which have helped to get things started. In the long term, however, it is necessary to figure out creative ways of using other resources.

Administrators are in the process of exploring day habilitation and residential habilitation funds available through New York's Medicaid home and community-based waiver. They are cautiously optimistic that they can use this funding to support their efforts. More specifically, they plan to use residential habilitation funds to cover services provided on weekends and for recreational activities. Day habilitation funds will be used to cover

opportunities that are developed in lieu of work. Staff keep narrative descriptions of their work as a way of providing accountability to funding sources.

In addition to being creative in their own financing, it has been necessary to encourage other agencies to look at funding in new and creative ways. For instance, administrators of the day treatment center in the situation described above had to figure out how to bill for services provided on a part day basis. Working with other agencies is one area in which Job Path has focused on building collaborative relationships.

Collaborating with Others

Collaboration with policy makers, other agencies and families has been essential to the development of services for people with severe disabilities. As Yvonne described, "You're coordinating with so many people--the families, maybe the day treatment center, or whatever agencies you're working with. And to get all those people on the right track, or maybe on the same track, that's a challenge." Job Path staff are committed to interdependent relationships with other agencies.

Gaining the support of policy makers. Chris Stone, Director of the Vera Institute, expressed the importance of working in collaboration with people who have decision making power and responsibility for funding in any effort to change or improve services. Administrators of Job Path consider partnership with key policy makers the foundation to their efforts. For example, the decision to support students transitioning from special education programs depended on two key people. Cooperation of a top administrator of special education services in New York City and a similar partner in the Office of Mental

Retardation and Developmental Disabilities (OMRDD) were crucial to the program's success. Administrators of Job Path not only rely on the support of these officials to initiate innovative projects, but rely on their support in implementing services. For example, Fredda explained how she depends on one local OMRDD official in particular to figure out how to use waiver funding.

In part, Job Path has unique challenges because there are very few agencies in New York City working to provide fully integrated services. It is essential to develop close working relationships with people who have power if change is to be made in a traditional and complicated bureaucracy.

Collaborating with other agencies. Because Job Path has historically provided services to only a few people with severe disabilities, moving in this direction has involved offering alternatives to people who receive services from other agencies. Administrators and staff have had to build collaborative relationships with day treatment centers, residential facilities, and schools. They have been pleased with the openness of some agencies.

One aspect of their relationship with other agencies has been to figure out complementary roles in the design and implementation of services. For example, in planning services for students transitioning from special education programs, Job Path staff rely on school personnel to help identify students' preferences and interests while they focus on developing opportunities.

Another aspect of collaboration with other agencies involved supporting colleagues as they began to think differently about people. For example, staff at a day treatment center were initially resistant to a man's involvement in activities outside of the center. He was

aggressive and they believed his behavior needed to change before he left the center. Lisa worked closely with staff to see that behavior was a sign that he needed more opportunities. She noted, "And sure enough, he's not without his issues, but he's not had any of the issues he had in the past." Over time, the two agencies developed a very cooperative relationship. Lisa explained, "They had teachers who had been there for 10 years who had the same people in their classroom, they wanted to see people move on too. So there was a real collective effort."

The fact that opportunities for people take time to develop has created some practical challenges for other agencies. Administrators have had to be willing to be flexible in their funding and regulations. For example, as explained earlier, day treatment centers have had to figure out how to support someone to attend part-time while exploring alternatives outside of that environment. This exploration is often challenging.

Working with families. Staff at Job Path respect the fact that people are part of families and that working together with them is necessary to their success. Yvonne stated, "What we do is more than getting someone a job. There has to be a relationship with the person as well as the whole family." They take direction from families to develop opportunities based on their lifestyles and preferences.

Their approach is very new to most families. For some, the experience of professionals coming into their home, listening to what they say, and suggesting new possibilities is new and different. Andrew explained:

> We go in to talk to families about what we're doing and what kind of possibilities are open by using our services. Some people, that scares them

and they run. We don't offer a school bus and a house for people to come and do things in, and that's a foreign concept to a lot of people, that's scary.

In the situations we observed, staff were sensitive to these concerns and by taking things slowly had developed not only cooperative relationships, but enjoyable relationships with people and their families.

People's Lives: Taking a Turn for the Better

We met several people who received services from Job Path during our visit. Each of them were at different points of exploration and pursuing new directions in their life. Stephen, Lillian, and James were three of those individuals.

Stephen

At the time of our visit, Stephen had been receiving services from Job Path for nearly two years. When staff met Stephen, he attended a day treatment center every day, full time. He began attending this center when he graduated from school and had been there for several years.

Although the day treatment center thought Stephen might be a good candidate for Job Path, they were convinced that he was not yet ready for a role in the community due to some apparently disruptive behaviors. However, Lisa and Andrew have spent a lot of time with the staff and Stephen, and they started slowly building on Stephen's interests outside of the center. Given this opportunity, staff at the day treatment center began to see his capabilities.

Stephen currently holds a part-time job at Wendy's and volunteers at a local animal shelter, where he plans to assist in walking dogs. After a period of time Andrew learned from Stephen that he would like to swim and so they have begun to explore options. We accompanied Andrew and Stephen to visit a pool in a local gym. This was one of several facilities they visited, and Stephen had to give some thought to the conflicting variables of cost and convenience. We walked with Stephen to a library near his home, where he intended to spend some time by himself perusing the shelves.

As mentioned earlier, one of the challenges with these activities consists of traveling from one location to another. Although Stephen does travel on his own, he has a tendency to confront people on the street. This is sometimes perceived as aggression, and could potentially be dangerous. This continues to be an area that staff address.

When we visited Job Path we had the opportunity to observe Stephen's last day at the day treatment center. We went to the center, where they had set up a party in the form of a graduation. Stephen seemed pleased, and people spoke of him warmly. Staff at the center appeared to view Stephen as a success story, if unusual in the sense that few people with his perceived degree of disability leave the center for jobs and activities in the community.

Lillian

Lillian is a 20 year old woman who lives with her mother and older brother in Brooklyn. She is in her last year of school and, unlike the majority of her classmates who will go to a day treatment center next year, she is pursuing opportunities to become involved in her community and develop her interest in children.

Yvonne has worked with Lillian and her family during this year of transition. Yvonne explained that what she is doing is very different than the transition program provided through the school. The school program provides a choice of five or six places for groups of students to visit, alternating so that they go to different places each day. The purpose is to explore their interests, but Yvonne explained how difficult it is in these situations for people to develop their individual interests because they are in groups and their choices are predetermined.

Yvonne admits that implementing an alternative approach is new for her and that she learns along the way. She spends time with Lillian and her family at least once a week. The agency currently funds Yvonne's time through grant money but plans to use day habilitation waiver funds in the future.

Because Lillian has very limited verbal communication it has been important that her mother and brother are closely involved in the development of services. Though Yvonne believes that working with the whole family is critical, it has been a challenge to negotiate their needs. Lillian's mother does not speak English, so most of the communication takes place through her older brother. Of primary consideration is the fact that the family considers the neighborhood where they live dangerous, and they are cautious about activities outside of the home. Yvonne has had to consider the family's lifestyle and concerns in assisting Lillian to develop relationships and become involved in outside activities.

Yvonne explained that they are moving forward slowly. For example, Lillian's family does not want her to travel alone, but Yvonne expects that they will agree to let Lillian receive rides from potential co-workers or friends.

Based on her interest in children, Lillian plans to volunteer at a day care center. At the time of our visit, Yvonne and Lillian had recently located a day care center that seemed to be a good match. Yvonne explained the importance of Lillian going with her to visit possible work sites as opposed to finding a place and then introducing her. Most importantly, she wanted Lillian's reaction to be the determining factor in making a decision. She also believed that day care administrators were more receptive when they had the opportunity to meet Lillian personally.

Yvonne had some initial ideas about how to support Lillian at the day care center. She, as well as Lillian's family, have considered the possibility that Lillian may be viewed more as a person who needs to be cared for rather than someone who can genuinely help out in this setting. Yvonne intends to discuss this with staff at the center and to arrange support so that at least initially, Lillian works closely with another adult which will help to establish her status. In addition to assisting Lillian at the day care center, Yvonne will continue to spend time with her and her family in the effort to develop other opportunities.

James

At the time of our visit, Job Path was in the process of planning services with James and his family. Though services for James were only at the planning stage, the difference between his past experience as determined by the service system and future possibilities through his involvement with Job Path were impressive.

James is a young man who lived for several years at a center that implements aversive behavior modification strategies with people who have severely self-abusive behavior. James

sometimes scratches himself uncontrollably to the point of breaking skin and pulls off his fingernails. These behaviors have been a life long problem and cause serious infections.

For much of his life, James lived in residential facilities and was treated with restrictive approaches in the attempt to control his behavior. His experience at the center, however, brought about a turning point in his life.

James and his family believed that the strategies employed by the center, including electric shock, were drastic but that the staff were convincing. James explained, "I thought I would give it a try." Though James explains that the electric shock in and of itself was not harmful, he was hurt very badly there. As he described, "It was the way they used it. They started using electric shock for every little thing I did. I would think, `What did I do wrong?'" He also explained how his meals were withheld because of his behavior.

James' parents were devastated by his experiences. His mother remembers thinking, "I can't eat if I know he's not eating... He was treated more and more like an object over time." His parents began the lengthy process of getting James released. During this time period, James visited his parents' home. The whole family recalled this visit in a tone of disbelief and outrage regarding the way James was treated. His mother explained that two nurses from the center accompanied him home and kept him under their control throughout the visit. She explained, "If they had to leave the room, to make a phone call or get something, they would drag James with them." James described being embarrassed by hourly "body checks" the nurses made each night in the presence of his sister.

James and his family knew that he needed to get out of the center but finding an agency that was willing to provide services was difficult. The family connected with Job

Path when Fredda heard about James' situation through a colleague and volunteered to develop services for him. Job Path had never developed services for someone who needed so much support. The agency relied on the help of consultants in this situation and work closely with officials to arrange funding. Most importantly, Lisa spends time getting to know James and his family. She, as well as other Job Path staff, have a very positive and personal relationship with them. This has been an experience that is very different for James and his family. Emily explained, "I think this is the first time that they've had an agency that's really willing to work with them as partners....We see them as partners and colleagues, working together."

Because the agency needs time to develop services and James needed to leave the center as quickly as possible, he moved to a nearby developmental center temporarily. He visits his parents often now with assistance from Job Path staff. We accompanied them to visit the family and learn about their plans for the future. Though the family shared many stories that were painful, there was a strong sense of excitement about the future.

James has chosen to live in his own apartment but is clear that he does not want a roommate. Since he lived at so many residential facilities, he explained that he is eager to have privacy and control over his home. It is anticipated that James will need one assistant 24 hours a day, at least initially. He has chosen a few people to provide assistance in his new home, all of whom he knew prior to this arrangement. One is an old friend who used to volunteer at a developmental center where he lived. At the time of this report, everything was in place and James was waiting for the budget to be approved before he could move.

Though developing a better living situation for James has been a priority, staff have begun to work with him to develop his interests. James is passionate about music, especially rap. His CD collection and stereo were impressive. He would like to eventually become a D.J. A year ago, this may have sounded far fetched but one gets the sense that this is a strong possibility. His family is supportive and excited about these possibilities. As his father concluded, "He's missed so much. There's a whole world out there he doesn't know."

In meeting Stephen, Lillian, and James, we felt a strong sense of new beginnings. Staff members believe they have just begun to tap the possibilities for these individuals. Their excitement is combined with the realization that they must continue to be open to learning and improving their work. In particular, they struggle in the effort to assist people to develop friendships. They are driven to accomplish this, however, as they consider the point at which a person has friends to be the mark of true success in their work.

Conclusion

We believe that the efforts Job Path has made to improve services are exemplary, particularly given that staff work in a large and complicated city. The most impressive aspect of their work was the fact that they move ahead without the benefit of others' experience and do so with great conviction.

The agency's strong philosophy of integration and the fact that it did not have a history of providing segregated services contribute to its capacity for developing a more responsive approach. Emily Ellis explained:

...in many ways in reflection and retrospect, I think there was a real advantage that we weren't kind of mired in the rehab way of serving folks with disabilities. Because we really believed from the very beginning that people had a right to work in the world, earn dollars, and be respected.

Job Path is one of the few agencies that has applied this philosophy to people with severe disabilities. In discussing the impact of their efforts, Emily concluded, "Fredda and I talk about where our role has had an impact on the social service community and it, particularly when you're working with severely disabled folks, is maintaining that quality of consciousness."

Job Path began to develop services for people with severe disabilities with the intention of breaking through the barriers imposed by traditional services and creating services which are more equitable. We believe the agency provides strong leadership in this effort.

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